

OUR MISSION

NAAF supports research to find a cure or acceptable treatment for alopecia areata, supports those with the disease, and educates the public about alopecia areata.

OUR VISION

An empowered community with a choice to embrace or live free of alopecia areata.

OUR VALUES

GROWTH: We create and nurture positive change for the future of our community.

RESILIENCE: We enhance the ability to mentally and emotionally cope with adversity.

ADVOCACY: We wield influence to create awareness and effect real change.

COMPASSION: We listen to understand and demonstrate care through meaningful support.

EMPOWERMENT: We build strength and confidence through connections, tools, and resources.



NAAF is a private, tax-exempt, nonprofit organization pursuant to Section 501(c)(3) of the Internal Revenue Code with Federal Tax ID# 94-2780249. All gifts and donations are tax deductible.

REFLECTIONS ON THE JOURNEY TO A TREATMENT

Imagine sitting in a conference room while a pharmaceutical research meeting is going on downstairs and you wish that one, just one, of those attendees would walk in and say, "yes, we are interested in finding a treatment for alopecia areata." Imagine being a NAAF Board member and receiving reports that experiments fail to bring any hair growth to research mice. Now fast forward 15 years to 2022 when numerous biopharmaceutical companies are not only interested in alopecia areata but are actually bringing those drugs to market! During those lonely days and negative reports, I always had hope; hope that our community would benefit from research and have a choice to take a drug to regrow their hair. 2022 brought us the FDA approval of the first drug to treat alopecia areata and the submission for the approval of a second drug. The research and additional approvals that are planned for 2023 and beyond are changing the future for those of us living with alopecia areata. Hope springs eternal!

Maureen McGettigan
Board Member and Past Chair

NATIONAL ALOPECIA AREATA FOUNDATION
65 MITCHELL BOULEVARD, SUITE 200-B
SAN RAFAEL, CA 94903
TEL 415-472-3780 | FAX 415-480-1800
INFO@NAAF.ORG | WWW.NAAF.ORG



NAAF Treatment Development Program 2022 Impact Report



"Big thinking precedes great achievement."
- Wilferd Peterson

In June 2022, the U.S. Food and Drug Administration (FDA) announced Olumiant as the first ever drug approved for treatment of severe alopecia areata. This was the culmination of big thinking combined with big action by the National Alopecia Areata Foundation (NAAF) community. It represents the successful outcome of two decades of focused effort by NAAF, the researchers NAAF funds and collaborates with, our industry partners, and our patient advocates—all made possible by NAAF donors.

Nearly a decade ago, then-Board Chair, Maureen McGettigan, clearly articulated the Foundation’s plan: to engage pharmaceutical companies with potential drugs, to call on the NAAF patient community to participate in clinical trials, and to advocate before the FDA with the goal of finding successful treatments.

This vision stemmed from a key moment in July 2010, which was a result, in part, of NAAF research investments. That was the month *Nature* magazine published an article “that unveils the most exciting genetic research on alopecia areata to date.” Led by then NAAF Scientific Advisory Council Member Dr. Angela Christiano, and using cases from the National Alopecia Areata Registry, a team of investigators from Columbia University Medical Center identified eight genes that contribute to the development of alopecia areata.

This discovery came in large part due to scientific leadership from NAAF in the form of research grants and sponsorship of the Registry, which provided the 1054 cases that enabled this breakthrough. The Registry was the largest collection of alopecia areata patient samples in the world, developed by Drs. Madeleine Duvic, Maria Hordinsky, Angela Christiano, David Norris, and Vera Price, with funding between 2000 to 2012 from the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

This was the breakthrough NAAF had been working toward. NAAF quickly established the Treatment Development Program to leverage all available research resources and clinical partnerships with the goal of achieving safe, effective, affordable treatments, useful to millions of people with alopecia areata. NAAF organized its first Clinical Research Summit on the Immunology of Alopecia Areata, thinking big and mapping out a path to achieve FDA-approved treatments.

Over the next decade, NAAF served as the primary convener of the alopecia areata research community, organizing summits, and increasing the number of key scientific publications to drive progress and attract new interest in the field.

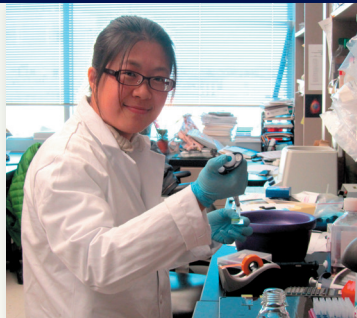

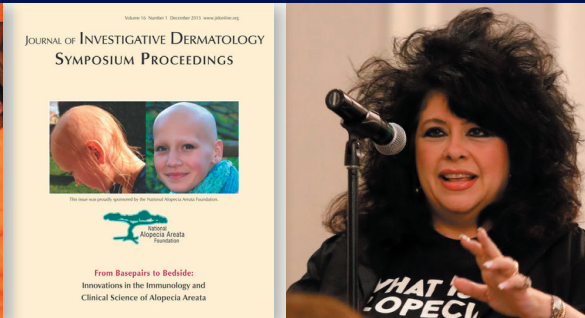



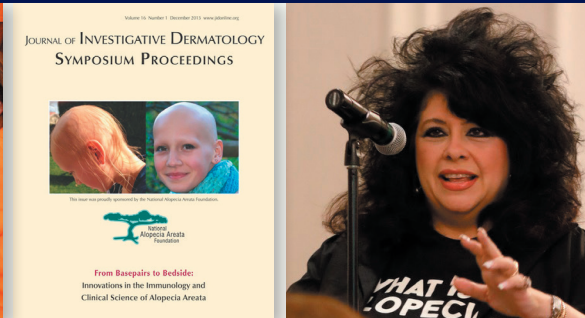


NAAF funding, and the esteemed members of its Research Advisory Council, also helped establish a uniform protocol for clinical trials.

In 2014, Dr. Brett King was the first physician to publish a report on successfully treating a patient with alopecia areata with a JAK inhibitor, and he has since played a key role in helping industry in developing medicines for alopecia areata.

For five years, NAAF patient advocates and researchers worked diligently for alopecia areata to be selected for a highly-coveted Patient-focused Drug Development meeting with the FDA. Upon acceptance in 2017, NAAF’s Health and Research Ambassadors, a team of patient advocates from research, scientific, and medical fields, helped mobilize over 400 patients across the country to increase the FDA’s understanding of the impacts of living with the disease, and the need to fast track progress toward approved treatments. The resulting “Voice of the Patient” report continues to be a landmark document that is frequently referenced in discussing the needs of the AA community.

2017 was also the year that NAAF formalized its partnerships with biopharmaceutical companies, establishing the Industry Partner Program and inviting a panel of industry leaders to share progress reports at NAAF’s annual Patient Conference. These partnerships have become a successful way to facilitate inclusion of the patient perspective in drug development programs, while also increasing support to NAAF’s mission and programs.

Looking back, the rigorous and tireless work of so many members of the NAAF community led directly to the 2022 milestone of the first FDA-approved treatment for alopecia areata. **And this is just the beginning!** We are entering a new era, with two more JAK inhibitors anticipated to be approved in 2023, and more treatments in trials now. We commend and thank the countless leaders, volunteers and donors who made this milestone possible. NAAF remains resolutely committed to its vision of creating more choices for our community.

2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2022
										
Genome Wide Association Study identifying 8 genes that contribute to alopecia areata is published NAAF initiates the Alopecia Areata Treatment Development Program	NAAF coordinates alopecia areata incidence, prevalence, and quality of life studies; funds the development of a Core Uniform Protocol for clinical trials	NAAF assumes financial responsibility of the Alopecia Areata Registry to leverage data and samples	Reports from NAAF’s 2012 Research Summit are published in the <i>Journal of Investigative Dermatology</i>	Key publications provide the rationale to use JAK inhibitors for the treatment of alopecia areata The first 4 clinical studies with JAK inhibitors show promise for re-growing hair	NAAF initiates the Health and Research Ambassador program to bring the patient voice into research design	NAAF embarks on an initiative to form a consortium with the intent of developing a patient-reported outcomes instrument	FDA grants fast track designation for CTP-543, an oral JAK inhibitor, for the treatment of alopecia areata Phase 2 clinical trials for alopecia areata are underway	FDA releases its <i>Voice of the Patient</i> Report NAAF coordinates publication of the article <i>Alopecia Areata is a Medical Disease</i> FDA grants breakthrough therapy designation for PF-06651600, an oral JAK inhibitor, for the treatment of alopecia areata	Large-scale phase 2 and pivotal phase 3 clinical trials for alopecia areata are underway	Olumiant, a product of Eli Lilly and Company, becomes the first treatment for severe alopecia areata approved by the FDA

